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FROM THE EDITORS

For this summer issue, we present to the readership a variety of pieces which have a largely medical anthropological flavour. Although this emphasis was not intended, it has been a most welcome outcome. We start things off with an update on the *Disability and Society Reader*, which shall shortly see publication. Innovia Director Stuart Blume provides a context for the development of the reader, and points to the importance of anthropological inquiry in areas related to disability studies.

We then introduce Deanna Trakas of the University of the Aegean, who walks us through three decades of professional experience as a medical anthropologist. Her narrative provides an excellent composite of compelling, sophisticated qualitative social science in health research, and an all too familiar reminder of the institutional resistances

that medical anthropologists (not to mention patients!) face as they vie, or even attempt to collaborate with medical practitioners to produce knowledge about health, illness, and disease. It is a gripping read.

From Deanna's bio, we move to a report from the International Alliance of Patients' Organizations (IAPO) on their 3rd Global Patients Congress, held in February this year in Budapest. The piece, written by IAPO Membership and Events Coordinator Esther Thompson, outlines the unique and visionary position IAPO has taken in the field of patient-centred healthcare, enabling international links and encouraging dialogue across and within disciplines and interest groups, with the aim of providing representation and support around the globe for patients, their families, and carers. We then turn to a report from a colleague in Nepal, Kapil Babu Dahal, who sketches out the field of medical anthropology in the country and argues, ultimately, for embracing forms of anthropological practice of particular relevance for the Nepalese population of today, including modes of collaborative work across professions and sectors, as well as topics that adequately address the global political context, disease burden, and health inequalities within the country itself.

From the editors here at the Innovia Foundation Newsletter, we wish you a pleasant rest of summer or winter, and hope you enjoy the content!

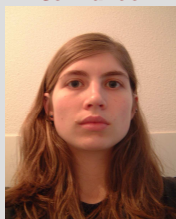
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NEWS FROM INNOVIA

Stuart Blume

A few weeks from now, if all goes well, the *Disability and Society Reader* that Innovia has edited on behalf of the Thai Program of Health Promotion for People with Disabilities will be published by Orient Longman in New Delhi. Wachara Riewpaiboon, Manager of the Thai Program, explained in Newsletter #2 (July 2007) that the motivation for commissioning this work was the continuing dominance of a *medical* model of disability in Thailand, and indeed in Asia more generally. The *social* model of disability, developed largely by American and British scholars (many of them people with disabilities) in the 1970s and 1980s is virtually unknown there. As most readers of this Newsletter will know, the social model of disability locates the barriers to the full integration of people with disabilities into society – the barriers to their citizenship – not in the body, but in society. Analysis and action must then focus on society's failure to make the necessary provisions and accommodations. Based on this, disability studies has emerged as a distinctive, emancipatory field of inquiry – in a few countries at least.

In collecting materials for the Reader, the editors (Renu Addlakha, Patrick Devlieger, Osamu Nagase, Myriam Winance, and I) were struck by the lack of studies focusing specifically on *technology* and disability that we could consider for inclusion. There are a few historical studies and collections [1] and of course there are numerous assessments of unmet need, especially in countries where many landmine victims live. A recent article in a leading journal of medical ethics explored some of the resource-allocation and other ethical issues raised by technologies for people with disabilities [2]. But why are there so few studies exploring access to technological aids, or people's satisfaction, or (above all) the *inventiveness* of people with disabilities? Could it be because 'assistive technology' is traditionally associated with rehabilitation

medicine, and so with the medical model of disability? There are a handful of studies, mostly by anthropologists, that illustrate what I have in mind. Susan Reynolds Whyte and Herbert Muyinda, for example, show people with disabilities living on the Kenya-Uganda border deploying technology in the service of their own independence and integration [3]. There are also a number of organizations devoted to working with people with disabilities in developing the technology they would like to have. Katrin Grüber has drawn my attention to one of them, CanAssist, the Canadian Institute for Accessibility and Inclusion, at the University of Victoria (www.uvatt.org). I have a strong feeling that there is work that Innovia could usefully do in this area, given its cross-national and cross-disciplinary nature. One question, for example, might be: How does the inventiveness of people with disabilities express itself in different cultural, social, and economic contexts? I'd like very much to hear from anyone interested in discussing further what Innovia could do.

May I finally draw readers' attention to two books recently published by Innovia Fellows? The first is by Renu Addlakha, called **Deconstructing Mental Illness: An Ethnography of Psychiatry, Women, and the Family** (ISBN 97881898840). The book is published by Zubaan Books of New Delhi. Costing 495 Indian rupees, it can be ordered from the publisher on-line. The second is Nicky Britten's **Medicines and Society: Patients, Professionals and the Dominance of Pharmaceuticals** (ISBN 0230205100). Just published by Palgrave Macmillan, it costs \$27.60. It can be ordered from Amazon.

[1] See for example Ott, K., D. Serlin & S. Mihm (eds) (2002) *Artificial Parts, Practical Lives. Modern Histories of Prosthetics*. New York: New York University Press.

[2] Sven Ove Hansson (2007) The ethics of enabling technologies. *Cambridge Quarterly of Healthcare Ethics* 16: 257-267.

[3] Susan Reynolds Whyte & Herbert Muyinda (2007) Finding people where they live: The view from a tricycle in Busia. In: Benedicte Ingstad & Susan Reynolds Whyte (eds) *Disability in Local and Global Worlds*. Los Angeles: University of California Press.

GETTING TO KNOW...**Deanna J. Trakas**

**Medical anthropology in Greece ...
Qualitative health research in Europe ...
Challenges ... and so on ...**

Several decades ago it was unusual for cultural anthropologists to be members of research teams investigating disease and health problems – unless there was an exotic factor implicated. We were called in to look at ‘cultural reasons’ to explain why indigenous people refused to use new sanitation facilities; offer ethnographic notes to explore whether *kuru* in the New Guinea Highlands should be seen as a culture-bound syndrome or a medical pathology; act as cultural brokers between microbiologists and the San of the Kalahari or the Yanamamo in the Amazon.

Today this picture has changed; anthropologists are increasingly engaged in egalitarian (rather than peripheral or middleman) dialogues with scientists from multiple disciplines involved in discourses about healthcare, illness realities, medical technology, and the human condition. I feel fortunate to have been part of this process. I’d like to introduce myself to Innovia with some stories about my research experiences.

From 1976-78 I conducted ethnographic fieldwork in Greek villages for my doctoral dissertation about acute haemolytic anaemia from eating broad beans (favism), and the g6pd deficiency. This was not exactly a mainstream topic, even for the newly emerging field of medical anthropology.

I returned to the US on a National Institutes of Health Fellowship, but eventually decided to temporarily go ex-patriot and take a position as a research associate at the Institute of Child Health in Athens. I was on a mission: to create a place for anthropology in multidisciplinary health research. Social anthropology was absent from Greek academia (along with, needless to say, medical



anthropology), and the curiosity of physicians and other health professionals about anthropology was easily satisfied with their conclusion that it was “something like social work”.

Initially I found a niche in multidisciplinary social epidemiology, assigned to coordinate data collection about children’s behavioural risk factors for heart disease (e.g. smoking, type A behaviour, exercise, health beliefs); a longitudinal follow-up of teenagers who had been exposed in utero to phenobarbital; and the outcome of labour in primipare (clinical trial of the *doula* system). These studies were part of larger projects and/or had substantial funding, and so provided an opportunity to see how these sorts of undertakings work at the level of coordination – a factor which would become crucial on the road I was travelling. Being involved with social epidemiology was consistent with the options available to the medical anthropologist of the 1980s; but I could observe an encroaching medicalization in my methodological approaches. This too was consistent with trends in the discipline at the time.

Occasionally I proposed small studies using ethnographic approaches and qualitative methods, e.g. an ethnography of a neonatal intensive care unit; a study of neonatal deaths in an agricultural province. However, the emphasis on quantitative research designs prevailed to such an extent that qualitative methodologies were considered not only as soft

science, but non-science. Comments during this time of my scientific career were not exactly the most encouraging and my attempts to dismiss them were obviously unsuccessful, as here they are some 22 years later:

The problem with anthropology in a medical research team is that it will never offer compelling answers about disease; medicine will always provide superior solutions to health problems and anthropology is not in the picture. (Professor, Medical School, USA – during a collaborative research project in Greece, circa 1984)

It seems to me that anthropology in medical research is the *crème de la crème*. We clinicians are trying to solve problems of life and death ... and I'm not really sure what you anthropologists can add to that. (Paediatrician, NICU, Greece, circa 1986)

Even so, encouragement came from the Maternal-Child Health European Office of the World Health Organization; for example, for a qualitative study of risk assessment in pregnancy based on interviews with obstetricians and midwives. Another modest project involved observations in pharmacies followed by visits with clientele, where a 'home medicine cabinet inventory' was used to guide interviews. In 1987 Graham Dukes, the Regional Officer for Pharmaceuticals WHO-EURO, suggested a study of cultural contexts in Europe related to medicine use. This was the beginning of new horizons, not only for me, but for a whole new network of junior and senior scientists from several disciplines.

In 1987, a qualitative study about children's perceptions of illness and medicines began in three locations. Lisbeth Sachs (Karolinska Institut, Sweden) and I worked on the idea of having children draw a picture of themselves the "last time they didn't feel well" as the stimulus for an 'interview' or discussion with them. The technique was implemented among 6-8 year-olds in Sweden, Greece, and the Netherlands. The study was used as the basis for a proposal to the European Commission. Developing a common language between the

qualitatively and the quantitatively oriented factions proved difficult. Indeed, the idea that a representative sample was not particularly important to the anthropologists was the first confrontation; virtually all other scientists at the meeting were dubious about the fate of a proposal that did not address this type of question. Following a series of debates about sample size and whether a handful of 'ethnographic informants' could constitute a study population, another set of questions were raised related to children as informants; e.g. Did they need to be tested for their IQ and developmental level? Could we trust them to tell the truth and not indulge in fantasy? The issue of truth and fantasy rarely seemed to be central in qualitative studies with adults, and anthropological views on 'objectivity' took the decibel level in the meeting room to new heights! We discovered that each word in the phrase "rational drug use" – along with the slogan itself – had totally different meanings for the anthropologists and the clinical pharmacologists (and, the medical sociologists as well).

In spite of an uneasiness that qualitative research would not be approved by the Commission – that more sophisticated quantitative methods were necessary to gain funding – I could not imagine coordinating yet another social epidemiological or quantitative project. It would be qualitative or ... nothing! Much to our surprise, the proposal was approved and we began a three-year concerted action about (healthy) children's perceptions of illness and medicines (1990-1993). As the project expanded to include new researchers, the issues raised above continued to follow us; i.e. the continued challenge of multidisciplinary research; the continued issues in qualitative approaches. Two additional concerted actions using qualitative methodologies were approved (1994-1997: "The Socio-cultural Management of Asthma in Childhood"; 1996-1999: "Living with Asthma in Childhood") allowing us to continue to work together and enjoy the perspectives which each member brought to the research team.

The rest is history; more information is available in three edited collections and a fourth that is, hopefully, going to press this summer (see references at the end). It is rewarding that comparative studies of the 'user's perspective' have become part of 'drug utilization studies'. At one of the first plenary sessions of 'The User's Perspective of Pharmaceuticals' (TUPP) circa 2000, the coordinator, Ebba Holmes Hansen (Social Pharmacy, University of Copenhagen) stated that the project would be a qualitative one. Virtually no one complained, no one asked about sample size, no one shifted uncomfortably in their chair. All I heard were the comments "Fine" and "Good idea". I thought to myself – times have changed.

This does not mean that the challenge of interdisciplinary research and problem solving groups has disappeared. Indeed, the tendency for the 'scientific' and 'objective' (quantifiable) perspective to absorb all other approaches is still very much part of discourses between

scientists from divergent research traditions. Meanwhile, the counter voices must continue to speak...

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[1] Bush P.J., D.J. Trakas, E.J. Sanz, R.L. Wirsing, T. Vaskilampi & A. Prout (eds) (1996) *Children, Medicine and Culture*. Binghamton NY: Pharmaceutical Products Press (subsidiary of Haworth).

[2] Trakas D.J. (ed.) (in press). *Focus Groups Revisited: Lessons from qualitative research with children*. Berlin: LIT Verlag.

[3] Trakas, D.J. & E.J. Sanz (eds) (1992) *Studying Childhood and Medicine Use: Perceptions and attitudes*. Athens: ZHTA Medical Publications.

[4] Trakas, D.J. & E.J. Sanz (eds) (1996) *Childhood and Medicine Use in Cross-Cultural Perspective*. Luxembourg: European Union.

IAPO'S 3RD GLOBAL PATIENTS CONGRESS

Esther Thompson

The International Alliance of Patients' Organizations (IAPO) was delighted to run its flagship event, the 3rd Global Patients Congress, which took place in Budapest, Hungary, from 20–22 February 2008. Patient representatives from all over the world met with healthcare professionals, policy makers, and industry representatives to discuss common challenges and issues of concern. The Congress provided an excellent opportunity to highlight important new developments in patient-centred healthcare worldwide.

The 3rd Global Patients Congress,



building on the success of the previous two Congresses held by IAPO in London and Barcelona, brought together over 180 stakeholders from around the world. IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. IAPO's members are patients' organizations working at international, regional, national, and local levels to represent and support patients, their families, and carers.

During the 1990's when IAPO was formed by patient representatives from around the world, it became clear that patients frequently face the same issues, no matter where they live or which health condition they are affected by. Issues such as access to adequate treatment and reliable and

comprehensive information are universally relevant. In order to create a strong voice that is capable of raising these issues across disease areas and continents, a number of organizations established a permanent coalition. Since 1999 when IAPO was officially registered as a non-profit organization, the Alliance has gone from strength to strength. We now have approximately 200 members, representing an estimated 365 million people worldwide, many of whom attended the Congress.

On the first day of the 3rd Global Patients Congress patient representatives had an opportunity to take part in capacity building sessions – to share their expertise and learn from each other's experience of fundraising, advocacy, and organizational development. The sessions provided exciting and inspiring opportunities to learn about the wide range of projects that patients are involved in worldwide. IAPO 'Twinning' workshops saw the initiation of several new projects between groups wishing to work together across regions. For example, one project was established to raise awareness about the stigma faced by patients with chronic conditions and another to assist patients living in other countries by translating information about healthcare services.

During the multi-stakeholder days of the event, key themes of Patient-Centred Healthcare, Patient Safety, Access to Healthcare, Patient Information, and Patient Involvement were explored through plenary sessions followed by several specific workshops on each of these themes. The aim of these sessions was to provide practical tools and advice for patient groups about how to take these issues forward. For example, Congress delegates gave feedback on IAPO's Patient Safety Toolkit, due to be launched later this year.

Plenary addresses demonstrated the central role patients are playing today in working towards patient-centred healthcare. Sir

Liam Donaldson, Chief Medical Officer UK & Head of the WHO World Alliance for Patient Safety, spoke about how patient experience can play a vital role in improving patient safety. Patients are catalysts for change, witnesses of the healthcare journey from beginning to end. Dr Linda Milan, WHO Western Pacific Region, Director of Building Healthy Communities & Populations, shared with us the progress of the people at the Centre of Health Care Initiative. Ms Katalin Rapi, Secretary of State for Health Policy, described government initiatives to provide meaningful support for the activities of patients' organizations in Hungary.

Members from different world regions shared their perspectives on patient-centred healthcare, and IAPO's work towards patient involvement. KP Tsang from the Alliance for Patients' Mutual Help Organizations outlined the work of this organization to raise the profile and understanding of IAPO's Declaration on Patient-Centred Healthcare in Hong Kong and China since its launch at the 2nd Global Patients Congress in 2006. In a country where it is not easy for patients get together to form formal patient organizations, KP stressed that the concept of patient-centred healthcare is groundbreaking and that the ideas in the Declaration were fresh and innovative for the groups that he works with.

Silvana Simi, from the Cochrane Consumer Council, explained that the 3rd Global Patients Congress in Budapest had focused on the benefits of patient participation in all the steps of healthcare, safety, and information. She commented that research shows evidence of the benefits of patient participation as patients possess unique expertise, coming from their being experts in the experience of their illness.

Overall the event provided a fantastic opportunity to develop understanding about patient-centred healthcare and to consider how we can work more effectively in the future to achieve positive change for all. Durhane Wong-

Rieger, IAPO Board Member and representative of the Canadian Organization for Rare Disorders, concluded that:

The Global Patients Congress has emerged as perhaps the most significant 'patient empowerment' event for patients from around the world. The Congress is a testament to what can be achieved when patients are empowered to help themselves and each other.

For further information about the Global Patients Congress, or to view photos, please go to our website:

www.patientsorganizations.org/congress2008

If you are interested in finding out more about IAPO's policy work or membership services, please contact info@patientsorganizations.org

MEDICAL ANTHROPOLOGY IN NEPAL

Kapil Babu Dahal

The Onset

In 1976 Tribhuvan University's Centre for Nepal and Asia Studies (CNAS) published a book on anthropological contributions in the field of health and illness. It covered a wide range of issues: reproductive health, healthcare and associated cultural factors, concepts of illness and curing disease, and the complex interactions between traditional healing practices and modern medicines. Most of the articles in this volume were based on research carried out in Nepal by scholars from abroad after the opening up of the country following the democratization process which began in 1950.

Though graduate training in anthropology began at Tribhuvan University in 1981 there are still no fully-fledged medical anthropology programs. And although some medical colleges have introduced courses in anthropological perspectives on health and illness, production of medical anthropological knowledge has remained largely the preserve of foreign researchers conducting their research

here in Nepal. Only recently have a few Nepalese scholars, including myself, who have received medical anthropological training abroad, begun to contribute in this arena.

Spheres of Medical Anthropological Engagement

Knowledge, beliefs, ideas, and practices relating to spirit possession have been a major focus for anthropological researchers in Nepal. The

embeddedness of spirit possession and its implications in everyday life and life consequences of people was so pervasive that it seemed all anthropologists would eventually end up analyzing these phenomena when approaching Nepalese society and

culture.

Some anthropologists have explored different aspects of foundations for plural therapeutic choices in Nepal. Along with the expansion of allopathic medicinal practices, recognized and promoted by the state as mainstream therapy, a few medical anthropological engagements (e.g. Streefland 1985 [1]) were directed to its interface with traditional therapies and its hegemonic position. Harper (2002) [2] has analyzed the broader political economic conditions into which the Vitamin A program falls, but also



symbolizes. For him this program has contributed to a massive rise in the consumption of pharmaceutical products over the last 15 years, and has enhanced the extraordinary power of biomedical hegemony on health.

Justice (1986) [3] has critically looked at the organizational culture of healthcare services in Nepal vis-à-vis that of donor agencies working for health promotion in Nepal. Besides examining the gap between policy making and program implementation in Nepalese healthcare services, she stressed the need to understand local cultural information if the healthcare system was to be improved. Many primary healthcare programs failed to become effective because they represented the perspective and needs of the health bureaucracies involved rather than those of the local villagers. Justice argued that social scientists, who are trained to analyze cultural contexts, can play a key role in helping international health bureaucracies be more sensitive to the local people they serve.

Numerous anthropological researches have focused on illness and suffering in Nepal. These studies have elaborated etiological factors, healing choices and procedures, and people's perceptions of different kinds of illnesses. Some of them have shown the social context of suffering, stigmatized condition of mental illness and how distresses are envisioned in relation to supernatural/spiritual forces e.g. *Bhut Lagnu* (attacked by ghost), *Saato Janu* (soul loss), and so on.

Kohrt and Harper (2008) [4] have analyzed the relationship between mind-body divisions, mental health, and stigma in Nepal. They have illustrated that the notion of mind-body divisions are not only a feature of the western Cartesian dichotomy but could also be central to understanding the self in non-Western settings. Patients and their significant others reject the notion that their illnesses are a result of an imbalance or dysfunction of the *dimaag* (brain-mind) in order to avoid the stigma of mental illness. Instead they

emphasize bodily explanations of distress. They have exemplified how everyday Nepali discourse on mind-body divisions offers a window into understanding social stigma against mental illness.

Based on their research about the *jhum-jhum* – the experience of paresthesia: a subjective numbness or tingling – Kohrt et al. (1995) [5] have critically looked at the research on depression in non-Western settings. Few such studies have rigorously considered possible physical explanations before diagnosing cases as 'somatization', and often come up with the simple generalization that the rates of somatization in non-Western groups are higher compared to those of the West. They claim that many somatic complaints in non-Western depression cases could be because of simultaneous psychological distress and physiological pathology.

Over the past thirteen years Nepalese society has been ravaged by violent political conflicts that have cost around thirteen thousands lives and have affected many more. Recent anthropological work has begun more specifically to address psychosocial wellbeing related to the conflict (Dahal 2007) [6]. Research findings have shown that the context, process, and repercussions of the conflict have shaken many people's place in society and severely affected their psychosocial health.

For most of the past 25 to 30 years medical anthropological researches in Nepal have concentrated on spirit possession, therapeutic choice, and child and maternal health. Only gradually have anthropological contributions on health and illness been moving away from a romantic glorification of existing knowledge, belief, attitude, and practices, towards rights-based approaches. Today however, health policy, conflict, and psychosocial health are acquiring increasing attention.

Future Prospects

Today many changes are collectively influencing the agenda for anthropological

researches dealing with health and illness in Nepal. They include the changing nature of the society as a result of expansion in education and critical awareness; emerging issues in global public health and the priorities of international aid agencies working in the country; development of health technology and its availability; the spreading out of allopathic medicines and pharmaceuticals; and growing attractions towards 'other'/traditional forms of therapies in urban areas. Much more attention needs to be paid to many other aspects, including issues and dynamics related with infectious diseases including HIV/AIDS; health inequality; psychosocial health; health policy; local ideas, knowledge, and practices in relation to aetiology and treatment of illness; relations between the healthcare seekers and the providers; hospital ethnography and infrastructural situation of health facilities.

Though still small in scale, some positive impacts of applied medical anthropological contributions have begun to emerge. Along with its critical linkages with the medical anthropological sphere at large, its engagement in Nepal has been expanding with promising future prospects. An important goal of medical anthropological engagement in Nepal, I think, should be improvement in health and wellbeing. For that, scholars from outside and from within can collaborate and work together, instead of "working in isolated islands". Likewise, I have witnessed and felt the need for multidisciplinary research and collaboration

among medical anthropologists, health professionals, organizations working in the areas of health and illness, and emerging patient organizations. To achieve that, I think that some major obstacles will have to be overcome, or at least minimized. They include the hegemony of medical sciences, and the barrier this forms to accepting the role of 'others', including the social sciences, in relation to healing illness and promoting health and wellbeing. They also include the inertia of all stakeholders, in preferring to stick to established and conventional roles. This is true in research too, and the lack of resources for collaborative multidisciplinary research must also be addressed.

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[3] Justice, J. (1986) *Policies, Plans, and People: Foreign Aid and Health Development*. Berkeley, Los Angeles, London: University of California Press.

[4] Kohrt, B. A. & I. Harper (2008) Navigating Diagnoses: Understanding Mind-Body Relations, Mental Health, and Stigma in Nepal. *Culture, Medicine, and Psychiatry*, December issue (forthcoming).

[5] Kohrt, et al. (2005) 'Somatization' and 'co-morbidity': A study of jhum-jhum and depression in rural Nepal. *Ethos* 33(1): 125-147.

[6] Dahal, K. B. (2007) Health Embedded in Social Context: Internally Displaced War Widows in Nepal. *The Journal of Finnish Anthropological Society* 32(1): 63-70.